Abstracts

Minisymposium 5

Research ethics

M5.1 DATA PROTECTION AND INFORMED CONSENT: A THREAT TO WORKERS' HEALTH

T. Norseth. *National Institute of Occupational Health, Oslo, Norway*

Trust seems to have been replaced by legal requirements in epidemiological research. Recent developments in biomedical research combined with developments in data processing technology, on the other hand, present problems unforeseen for personal integrity, research possibilities, and economical exploitation. We will discuss some of these problems by a case presentation and evaluation, and by discussing ethical problems concerning biobanks.

M5.2 EXPOSURE AND HEALTH EFFECTS AMONG WORKERS IN THE NORWEGIAN SILICON CARBIDE INDUSTRY

M. D. Bugge. *National Institute of Occupational Health, Oslo, Norway*

Workers in the silicon carbide industry have an increased risk for lung cancer and other pulmonary diseases.
Our study is an epidemiological project where a detailed job exposure matrix, and individual health data, such as cancer registry data and old pulmonary *x* rays, among others, will give us the opportunity to calculate any dose-response relations between several exposure factors and health effects. To get valid results we need as complete cohort as possible. The Norwegian Data Inspectorate issued a licence requiring explicit consent from all study subjects still living. We appealed to the Privacy Appeal Board, and the Board decided in favour of our appeal.

M5.3 BALANCING PUBLIC INTERESTS AGAINST INDIVIDUAL DISADVANTAGES USING PERSONAL DATA IN EPIDEMIOLOGICAL RESEARCH

K. W. Ruyter. *National Committees for Research Ethics in Norway, Oslo, Norway*

The main aim of the presentation is to discuss when it is appropriate to balance interests in epidemiological research (public interests *v* possible individual harm). In the decision by the Appeal Board in the case of the silicon carbide industry it presupposed scientific necessity before the weighing of interests was allowed. Then it was also appropriate to obtain passive consent (to strengthen privacy and reduce harm). This legal decision is compared to ethical reviews—for example, the quality of research and its potential benefits, the importance of paying attention to what type of research, flexibility in the acceptance of what is considered valid consent, etc. Could the silicon carbide project have been approved without any kind of consent? What are the consequences for planning future research projects in epidemiology?

M5.4 RESEARCH ETHICS WITH SPECIAL REFERENCE TO BIOBANKS

P. Westerholm. *National Institute for Working Life, Stockholm, Sweden*

The conceptions of integrity, autonomy, informed consent, and trust in epidemiological research are commented upon in the light of issues arising from establishments of biobanks. Biobanks collect different types of information and material—on tissue samples, on subjects submitting samples, on physicians and hospital units involved, diagnoses and treatments, information obtained from samples by methods of genetic engineering, etc. Management of biobanks may involve conflicts between donors, relatives of subjects, owner of biobank, research, and industry. Issues of informed consent extend beyond the traditional requirements on information and consent in biomedical research.